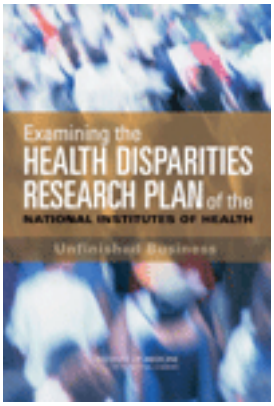
Free Executive Summary



Examining the Health Disparities Research Plan of the National Institutes of Health: Unfinished Business

Gerald E. Thomson, Faith Mitchell, Monique Williams, Editors, Committee on the Review and Assessment of the NIH's Strategic Research Plan and Budget to Reduce and Ultimately Eliminate Health Disparities

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Executive Summary

ABSTRACT

This report is an assessment of the National Institutes of Health (NIH) Strategic Research Plan and Budget to Reduce and Ultimately Eliminate Health Disparities and the adequacy of coordination of the development and implementation of the Strategic Plan across NIH Institutes and Centers.

Congressional legislation in 2000 called for the establishment of the NIH National Center on Minority Health and Health Disparities and a Strategic Plan to address the continuing poor health states of minorities, those with low income, and people living in rural areas. The plan includes the strategic plans of 25 Institutes and Centers and 2 Offices within the Office of the Director. Goals and objectives in research, research capacity, and communication are expected to form the foundation for the NIH health disparities research program.

The study committee viewed the Strategic Plan in the context of the need for NIH health disparities research to be conducted as an integrated and inclusive field of study rather than an aggregate of independent research plans and activities occurring in separate research domains. Such an approach, for example, would help to further needed study of social, behavioral, environmental and other root factors interactive across diseases, conditions and affected populations. As well, there would be more assurance that needed areas of research are not neglected.

A concerted minority health and health disparities research program and its Strategic Plan is a challenging trans-NIH effort because of the scope and complexity of the research, and the NIH organizational and functional setting that makes it difficult to manage initiatives across NIH. Development and implementation of the Strategic Plan presently lack the central management and coordination necessary to meet the challenge. Development and revision of the Strategic Plan has been delayed and incomplete. The Committee did not find organized, collective involvement of the Institutes and Centers and expertise from outside of NIH in overall planning. The Plan includes extensive programs in the Institutes and Centers, without evidence that these efforts are centrally coordinated, appropriately assessed regarding priorities and outcomes, or otherwise viewed as part of an overall NIH strategy. Continuous, effective, and demonstrable trans-NIH coordination and management with clearly established responsibility and authority should be assured by the Director of NIH through the Director of the National Center on Minority Health and Health Disparities, including timely updates of the Strategic Plan and collective involvement of the Institutes and Centers in overall planning and implementation, monitoring, and evaluation of the Strategic Plan and the health disparities research program.

Needed additions to the Strategic Plan include attention to the integration of research on the multifactorial nature of health disparities; population research; targeted and timed objectives; collaborative, integrated research on disparate health care; identification of additional affected populations; access to a registry of conditions for which differences between populations exist; assessments and evaluations of programs intended to increase institutional and research-personnel capacities to conduct health disparities research; and attention to public and professional communication regarding health disparities as a specific, trans-NIH program.

The health of racial and ethnic minorities, poor people, and other disadvantaged groups in the United States is worse than the health of the overall population. National concerns for these differences, termed health disparities, and the associated excess mortality and morbidity have been expressed as a high priority in national health status reviews, including *Healthy People 2000* and *Healthy People 2010*. The National Institutes of Health (NIH) ranks this issue third among its top five priorities.

Research is fundamental to the understanding and ultimate correction of health disparities. The needed research is as far-ranging and complex as the disparities. Involved are biomedical factors that span the entire range of medical specialties and research domains—and these factors are strongly intertwined with vital social, behavioral, and population research issues, as well as disparate health care.

As the nation's foremost research agency, NIH plays a leading role in health disparities research. Although NIH has accomplished much important research related to health disparities, there has been concern that NIH ensure that research efforts are optimally marshaled to address health disparities. The Minority Health and Health Disparities Research and Education Act of 2000 (P.L. 106-525) delineated NIH's role in improving minority health and reducing health disparities. The legislation called for the establishment of the National Center on Minority Health and Health Disparities (NCMHD) to administer special grant programs, coordinate minority health and health disparities research across NIH and lead the development of an NIH-wide strategic plan on health disparities. Detailed descriptions of NCMHD's responsibilities and mandates are included in the legislation (see Appendix A). Established in 2000, NCMHD directed development of the NIH Strategic Research Plan and Budget to Reduce and Ultimately Eliminate Health Disparities, which was completed in 2003.

CHARGE TO THE COMMITTEE

In 2004, the 4th year of the NIH minority health and health disparities initiative, NCMHD asked the Institute of Medicine to:

- Assess the adequacy of the trans-NIH minority health and health disparities Strategic Plan in achieving the NIH's goals and objectives. Specifically, the Committee was to evaluate the Strategic Plan with respect to:
  - Research (e.g., How well does the Strategic Plan advance scientific understanding of the causes and means to reduce and ultimately eliminate the disproportionate burden of disease among health disparity groups?),
  - Research Infrastructure (e.g., Does the Strategic Plan adequately expand opportunities and the institutional capacity—such as the environment, leadership, and commitment to health disparities research—for research on health disparities?),
  - Public Information and Community Outreach (e.g., How adequately does the plan address needs for the dissemination and application of research findings to reduce and ultimately eliminate health disparities?);
- Assess the adequacy of coordination across NIH ICs in helping to develop and carry out the Strategic Plan and avoid duplication of administrative resources among ICs and divisions; and
- Identify means, including potential legislative modifications, to help NIH achieve its minority health and health disparity Strategic Plan objectives.

In its approach, the Committee reviewed the challenges and needs of health disparities research and analyzed (a) the adequacy of the Strategic Plan as a document and plan of action, including the ICs' individual strategic plans; (b) budget information; (c) trans-NIH organization of the efforts; and (d) experiences

with implementation, coordination, and monitoring. The process included open meeting sessions with the directors of NIH and NCMHD, directors and leaders of several large ICs and Offices within the Office of the Director, and individuals and representatives of numerous government agencies and private organizations concerned with health disparities. Commissioned papers and a commissioned survey were used to further inform the Committee.

HEALTH DISPARITIES: DEFINITIONS, MEASUREMENT, AND UNDERSTANDING

Understanding and correcting the poorer health of populations in the United States is complicated by the need for more consensus on definitions, the wide range of diseases and conditions, a variety of causal factors, and varying measurements of factors and their interactions. Even as research and attention to correction move ahead, core questions and issues need more focus. NIH should take leadership in helping to further define, measure, and better understand health disparities, and also help to guide attention to research needs and opportunities.

Findings:

- **Lack of consensus regarding conceptual and operational definitions of disparities and the complexity of measuring health and health determinants pose challenges for the identification, understanding, monitoring and elimination of health disparities.**
- **There is a continuing need for NIH-funded research to develop, test, and refine measures and conceptual approaches for assessing and monitoring health disparities. Research is required to answer fundamental questions: Which factors are most critical to monitor? How can they best be measured?**
- **Currently available information does not provide a full and accurate description of disparities between, and within, racial and ethnic groups and across the full spectrum of socioeconomic status. Detailed, accurate data on Hispanic, Asian/Pacific Islander, African American, and American Indian/Alaska Native subgroups are needed, including data on income, education, and occupation. Such data will provide an important source for research on disparities and for monitoring progress toward reducing and eliminating disparities across the nation.**
- **Sophisticated and creative approaches to studying the processes that cause health disparities are needed. Coordinated, collaborative trans-NIH initiatives, with the active involvement of multiple ICs, will be needed to understand common backgrounds for multiple diseases. Coordinated, collaborative trans-agency approaches will be required to successfully investigate the complex relation-**

ships and interactions among race, ethnicity, gender, income, education, occupation, immigrant generation, and area of residence.

Recommendation: NIH, through NCMHD and the ICs and, when appropriate, collaborating agencies, should undertake research to further refine and develop the conceptual, definitional, and methodological issues involved in health disparities research and to further the understanding of the causes of disparities.

For such research, priority areas should include, first, the development and refinement of valid measures of exposures relevant to understanding and evaluating health disparities. For example:

- Interagency disparity research initiatives to develop valid and reliable measures of health effects of social factors; genetic risk; stress; racial/ethnic discrimination; and health care access and quality.
- Disparities research embedded into large studies (molecular, clinical, and epidemiological), national data sets, and public health monitoring measures through the greater inclusion of appropriate measures of race, ethnicity, socioeconomic status, and residential characteristics, and of the psychosocial and environmental factors that are likely to shape health disparities in the population being studied at each time point of data collection.
- In population-based studies, the inclusion of information on racial and ethnic subpopulations and other relevant characteristics, such as immigrant status, language preference, and detailed socioeconomic data, should be encouraged. Investigators funded by the ICs should be encouraged to gather information on socioeconomic status and other dimensions of social stratification.

Second, priority areas should include initiatives to further enhance understanding of the etiology of health disparities. For example:

- Multidisciplinary initiatives to advance the study of disparities, including gene-environment interactions and biological mechanisms mediating disparities.
- Trans-NIH disparity research initiatives to elucidate the pathways and mechanisms by which health disparities occur, including the identification of common backgrounds for multiple diseases and disease-specific mechanisms that may facilitate the development of strategies for intervention.

DEVELOPMENT OF THE STRATEGIC PLAN

Creation of the extensive Strategic Plan included the development of individual strategic plans by 25 of the 27 ICs and 2 Offices within NIH's Office of the Director, followed by reviews and approvals, including those of NCMHD and the

director of NIH. Although development of the Strategic Plan began before the legislation and the establishment of NCMHD, the first Strategic Plan, that for 2002–2006, was not available until 2003. It was expected, both by the legislation and as described in the initial Strategic Plan, that the Strategic Plan would be revised and updated annually. The only updated Strategic Plan, that for 2004–2008, was available to the review committee late in Fiscal Year 2005 as an incomplete, unapproved draft without a budget.

Finding: NIH has not updated the Strategic Plan as intended by the legislation and the NIH.

Recommendation: The NIH director should assure that the Strategic Plan is reviewed and revised annually using an established, trans-NIH process subject to timely review, approval, and dissemination.

THE STRATEGIC RESEARCH PLAN AND BUDGET

Although the only complete and approved Strategic Plan available for review was the 2002–2006 Strategic Plan, the Committee felt that it would be most helpful to include a review and assessment of the unapproved Strategic Plan for 2004–2008.

The Strategic Plan has three goal areas: research, research capacity, and outreach and communication (see Box 3-1 and Table 3-3 in Chapter 3).

The **research goal** forms the basis for substantial objectives that properly address the understanding of diseases and disabilities, detection and diagnosis, prevention, treatment, and, in the 2004 Strategic Plan, attention to the multifactorial causes of health disparities. Additional research objectives warrant emphasis and inclusion.

Minority health and health disparities research should include attention to the nonbiological and biological multifactorial background of disease and disability. Integration of such aspects of research with activities related to the Strategic Plan objective dealing with "understanding . . . the development and progression of diseases and disabilities that contribute to minority health and other disparities" should be encouraged. The need for information on health disparity populations should also be an objective of the Strategic Plan. Recognition of the relationship between health care disparities and disparities in health status is not currently described in the Strategic Plan. Opportunities for collaborative, interagency research in health care disparities should be fostered by a specific objective.

Finding: The Strategic Plan has placed inadequate emphasis on understanding social and behavioral determinants of health and their interaction with biological factors; better understanding of the characteristics of populations affected by poor health and the characteristics of diseases

and conditions for which disparities exist in those populations; the relationship between population disparities in health care and differences in health status; and research opportunities regarding disparities in health care.

Recommendation: The Strategic Plan research objectives should promote more integration of research on the multifactorial nature of health disparities, including nonbiological factors; population research to further the understanding of the presence, prevalence, trends, and other elements of health disparity conditions; and, when opportunity exists, an understanding of the causes of disparities in health care.

The **research capacity** goal and the listed objectives were found to be appropriate by the Committee. The Committee emphasized the importance and potentials of certain aspects of the objectives—specifically, diversity in the scientific workforce, the participation of minority individuals in clinical trials, community-based participatory research, and the need for assessments of programs.

Diversity in the scientific workforce, and an increase in the numbers of researchers who will engage in health disparities research, are important objectives. During the minority health and health disparities research program and the implementation of the Strategic Plan (2000–2004), successes and trends in providing support for the development of researchers so far have varied with the type of career-support mechanisms. Minority Research Fellow and Research Career Awards increased, but Research Training Grants for minorities changed little. Participation of minority individuals in clinical trials did increase during this period.

The Strategic Plan's objectives should include assessments of the results and impacts of research infrastructure programs (including institutional awards) on the capacity to conduct minority health and health disparities research. This information is needed to evaluate the effectiveness of programs, identify approaches in need of modification, set priorities, and make evaluations available for internal and external reviews.

Community-based participatory research can be a valuable, if challenging, research approach. The Strategic Plan and the health disparities research program provide an opportunity to analyze and evaluate community-based participatory research in health disparities research and to generate experience-based guidance on its use in future health disparities research efforts. NCMHD can play a central role in fostering the understanding and application of community-based participatory research in health disparities.

Findings:

- **The Strategic Plan does not provide for assessments of the results of the research capacity and infrastructure programs included as**

objectives. Such information is needed to evaluate the effectiveness of these programs, identify approaches in need of modification, set priorities, and make evaluations available for internal and external reviews.

- **The inclusion of community-based participatory research as an objective of the Strategic Plan is appropriate. There is a need for development of metrics, analysis, assessment and evaluation of community-based participatory research for a better sense of the issues and settings for which it is most promising.**

Recommendation: The Strategic Plan should include measurable targets and time periods for the research capacity objectives. NIH, through NCMHD's oversight, should develop methods of measuring, analyzing and monitoring the results of programs that address research capacity, including workforce, institutional, infrastructure, and community-based participatory health disparity research objectives.

The objectives listed in support of the **community outreach, information dissemination, and public health education goal** are reasonable. There are important areas in which more information is needed to improve public information and outreach strategies related to health disparities, including attention to the complexity, difficulties, and challenges of communication and the need for an organized, coordinated, trans-NIH approach to the communication effort.

Finding: The current objectives for outreach and public information identify target audiences, but attention is needed to issues of inequalities in public communication, including those related to access and use of, and ability to act on, information. Additional understanding is needed regarding effective communication with those who provide care to groups with poor health. Coordination of communication programs across NIH could help with examination of specific audience needs and evaluations of programs.

Recommendation: The Strategic Plan's communication programs should be organized as a specific trans-NIH effort with centralized coordination with particular attention to the strategic planning, design, prioritization, implementation, and evaluation of efforts across NIH. The initiative should: be informed by advisory expertise; develop a surveillance system to identify information needs and availability, sources, behaviors, and use patterns; and promote attention to the issue of inequalities in health communication.

THE STRATEGIC PLANS OF THE ICS

The Strategic Plan's goals and objectives cannot be achieved unless they are adopted by the ICs and reflected in their objectives and activities. The individual strategic plans of the ICs contain an impressive array of planned activities related to the overall Strategic Plan objectives, but some overall objectives appear infrequently as intended IC activities. Time-based, targeted research activities would help with assessments of the results of research programs.

Finding: There is no evidence that the strategic plans of the ICs were developed as part of a concerted, trans-NIH strategic planning process. Planned IC activities are not time-based or targeted.

Recommendation:

- **The development of updated Strategic Plans should include assessments of the appropriateness of the individual strategic plans of the ICs, including whether they adequately reflect the overall goals and objectives of the NIH Strategic Plan.**
- **Objectives should be time-based and targeted with measurable outcomes.**

HEALTH DISPARITIES AS DEFINED BY THE STRATEGIC PLAN

Although defining health disparities is difficult (see Chapter 2), the Strategic Plan and the minority health and health disparities research program required working definitions. The legislation and the Strategic Plan indicate that in addition to racial and ethnic minorities and low socioeconomic and rural populations there may be other population groups that warrant inclusion in health disparities research and the Strategic Plan. As described by the legislation, it is expected that the director of NCMHD, consulting with the director of the Agency for Healthcare Research and Quality, will, when appropriate, designate additional groups experiencing diseases and conditions for which there are disparities. Such designations should be the result of a well-informed process with specific criteria.

Findings:

- **Beyond the basic definitions of health disparities indicated by Congress and used by NIH, there are no further criteria for deciding what constitutes a health disparity group. Understanding the health impacts of social stratification (e.g., in the education system or the labor market) presents an additional approach to health disparities research.**
- **There is need for a resource that provides updated listings of: diseases and conditions for which differences exist; affected popu-**

lations; prevalence data; and other information that would provide a knowledge base on the scope and impact of disparity conditions. This resource would help in planning health disparity studies, setting priorities, and assessing research activities.

Recommendation: NCMHD should consider the designation of additional health disparity groups based on an informed process and developed criteria. It should promote development of, and access to, a registry of diseases and conditions for which disparities exist with regard to race, ethnicity, socioeconomic status, geographic locale, and other designated health disparity populations.

THE STRATEGIC PLAN BUDGET

The first Strategic Plan, for 2002–2006, and the 2001 Annual Report included budgets developed without uniform accounting, coding definitions, and methodologies for attributing research activities to minority health and health disparities efforts. The second Strategic Plan (2004–2008) was available for review as an unapproved draft that did not include a budget. The two subsequent Annual Reports, for 2002 and 2003, were also incomplete and unapproved.

The enabling legislation recognized the need for incremental funding to be provided to the NIH and authorized up to $100 million in additional annual funding for minority health and health disparities research to be added to separate appropriations for the conduct and support of the health disparities research program, but the incremental funds were not allocated to the NIH. The committee expressed concern that the absence of such funding might have impeded the establishment of new health disparities research programs, which would reasonably incur additional research and management costs.

Regarding the ways in which budget information is reported, it would be helpful to have budget information categorized by funding for each goal area, along with the funds allocated for each objective under each goal, and individually for each involved IC and office. Such information would facilitate monitoring and review.

Findings:

- **Incremental funding was not provided to NIH for the minority health and health disparities research program.**
- **As of July 2005, during the 5th year of the program period, no complete, standardized, approved budget information was available from the Strategic Plan or the Annual Reports. The absence of such information calls into question the validity and efficacy of the Strategic Plan and Annual Reports as tools for planning and coordination.**

- **For more accurate evaluation, detailed information on specific categories and aspects of the minority health and health disparities research program and the Strategic Plan would be helpful.**

Recommendation: Within NIH, a clear and timely budget process should be linked to the Strategic Plan, and it should be updated in a timely manner. Annual budgets should include information for NIH as a whole, and for each involved IC and Office, and should detail allocations for the Strategic Plan goal areas and each objective. Trans-NIH budget information on efforts made in the major categories of research, research capacity, and communication also should be made available.

Based on information provided by the NIH Budget Office, the Committee attempted to compare funding for minority health research (involving minority populations) and health disparities research (minority health plus groups with low socioeconomic status and rural populations) for the years 1998 through 2004, though (except for 2003 and 2004) the data were not standardized. The application of new, standardized definitions of minority health and health disparities in Fiscal Year 2003 apparently changed the reported NIH funding for minority health research, from $2.13 billion to $2.09 billion, and changed the estimate of funding for health disparities research from $3.16 billion to $2.43 billion. Using the old methodology, the percentage of the NIH total budget attributed to health disparities research was calculated to be 11 percent in 1999, and 12 percent each year from 2001 to 2003. With the new methodology it was 9 percent for 2003 and 2004. In comparison, the proportion for minority health research held at around 8 percent from 1999 to 2004, reflecting the fact that during the period in which the NIH budget doubled (1998–2003), spending on minority health research kept pace.

THE NCMHD

The Office of Research on Minority Health, established in 1990, became NCMHD in 2000 as a result of the legislation (P.L. 106-525). The legislation also prescribed NCMHD's dual responsibilities: (a) the administration of large, legislatively mandated grant programs dealing with research infrastructure and capacity; and (b) service as the hub of responsibility for coordinating and managing the Strategic Plan. The Committee questioned NCMHD's current resources and capacity to deal with these responsibilities.

Findings:

- **The dual roles of NCMHD as a granting center and as a coordinator of major trans-NIH efforts are unique. The leadership of NCMHD and its Advisory Council call attention to the need for increased administrative staffing for NCMHD.**

- **There is a need for increased science leadership and presence in NCMHD, particularly for proper management of the trans-NIH initiative.**

Recommendation:

- **The NIH director should review and assess the administrative staffing of NCMHD to ensure that it is sufficient to attend to the Center's responsibilities.**
- **Increasing the science leadership and presence within NCMHD should be pursued by the NIH and NCMHD directors. This entails the appointment of additional eminent scientists, recognized in the areas of minority health and health disparities, and the establishment by NCMHD of committees and panels with relevant expertise from within and outside NIH.**

MANAGEMENT AND COORDINATION OF THE STRATEGIC PLAN AND MINORITY AND HEALTH DISPARITIES RESEARCH

The breadth and complexity of the health disparities research agenda and the Strategic Plan present an extraordinary challenge for trans-NIH management. To best manage these efforts, NIH needs to:

- Ensure concerted involvement of the ICs and Offices to develop and regularly update the Strategic Plan;
- Ensure that all ICs and pertinent Offices are attentive to the Strategic Plan's mission, goals, and objectives;
- Avoid gaps, such as populations, conditions, needs, and approaches, that would otherwise not be identified or addressed by the independent operation of the ICs;
- Involve the best expertise from across the NIH and from the external scientific community;
- Avoid duplicating administrative and research efforts;
- Facilitate collaboration and coordinated research approaches;
- Coordinate outreach and communication;
- Create an organized program structure for effective monitoring and research articulation with other government agencies; and
- Devote attention to research and budget priorities.

The potential for conflicting priorities is real. The ICs' budgets reflect commitments, mandates, and priorities resulting from budget presentations to, and authorizations from, Congress. If there is truly a concerted trans-NIH priority for minority health and health disparities research, which is stated to be third among

the agency's top five priorities, then this concern should be active in priority formulations and decisions within the ICs.

Development of the Strategic Plan does not involve the coordinated, concerted, and collective participation of the ICs. There is no ongoing, continuous update process with an established trans-NIH structure involving the ICs and others to produce planning improvements and results in periodic, meaningful updates and revisions of the Strategic Plan. There is no evidence of trans-NIH planning of priorities regarding minority health and health disparities research activities and resources for the NIH as a whole or with respect to the ICs. In discussions with the Committee, directors and other leading members of several large ICs with extensive minority health and health disparities programs expressed a very high level of commitment to and enthusiasm for these activities. However, it was evident that there had been little to no contact with the NCMHD during the development or implementation of these projects and programs. Activities and programs were pursued independently of NCMHD, except that some, particularly in the past, had been co-funded, or sometimes totally funded, by NCMHD.

There is no manifest organizational structure for the trans-NIH Strategic Plan and health disparities program. Advisory and coordinating committees are not described or apparent. Experts from scientific, health care, and affected communities are not involved in advising and participating in ongoing planning in established, structured, predictable ways. The result is a gaping lack of opportunity to properly inform and contribute to the identification of research and related needs, plans, and strategy.

No results summarizing the monitoring and assessment of minority health and health disparities research, and related activities for the NIH, or with respect to the ICs, are evident. Annual reports are late, languish incomplete and unapproved, and do not contain evidence of central NIH assessments of research and program activities. Moreover, budget and finance issues are not addressed by a centralized entity responsible for the minority health and health disparities research program and the Strategic Plan.

The Committee saw the need to be certain that there is clearly designated authority to coordinate and manage the Strategic Plan and health disparities research program. Although the legislation indicates that the NCMHD director is responsible for coordinating all NIH minority health and health disparities research, the responsibility for monitoring and managing the Strategic Plan and the program falls on the NIH director, the NCMHD director, and the IC directors. The text of the approved initial Strategic Plan (2002–2006) indicates that NCMHD is responsible for such functions, but it was unclear to the Committee whether this authority is widely understood.

Finding: The level of trans-NIH coordination needed to effectively implement the Strategic Plan has not been evident. Instead, the Committee

concluded that an uncoordinated, unmonitored, loosely administered trans-NIH program existed, with substantial commitments and activities of largely independent ICs, but without the coordinated, concerted program needed. Clarity regarding the responsibilities and authority may be a factor in achieving more effective management. The mandates of the NIH director are key elements in structuring and assuring effective management.

Recommendation: The NIH director, through the established authority of the NCMHD director, should ensure continuous, effective coordination of the health disparities research program across NIH, including:

- **Timely development of Strategic Plan revisions;**
- **Effective, ongoing participation of the ICs in the Strategic Plan and the health disparities research program;**
- **Establishment of appropriate committees involving the directors of the ICs and others to facilitate collaboration and coordinated approaches to health disparities research and the setting of priorities;**
- **Fostering of conferences and the use of committees and panels involving the NIH, extramural scientific communities, and others to inform and advise on initiatives and directions; and**
- **Monitoring of the execution of the Strategic Plan to ensure that its elements are implemented.**

Examining the HEALTH DISPARITIES RESEARCH PLAN of the NATIONAL INSTITUTES OF HEALTH

Unfinished Business

Committee on the Review and Assessment of the NIH's
Strategic Research Plan and Budget to Reduce
and Ultimately Eliminate Health Disparities

Board on Health Sciences Policy

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The serpent has been a symbol of long life, healing, and knowledge among almost all cultures and religions since the beginning of recorded history. The serpent adopted as a logotype by the Institute of Medicine is a relief carving from ancient Greece, now held by the Staatliche Museen in Berlin.

"Knowing is not enough; we must apply.
Willing is not enough; we must do."
—Goethe

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COMMITTEE ON THE REVIEW AND ASSESSMENT OF THE NIH'S STRATEGIC RESEARCH PLAN AND BUDGET TO REDUCE AND ULTIMATELY ELIMINATE HEALTH DISPARITIES

GERALD E. THOMSON *(Chair),* Lambert & Sonneborn Professor of Medicine, Emeritus, Senior Associate Dean, Emeritus, Columbia University College of Physicians and Surgeons, New York, NY

JOHN F. ALDERETE, Professor, Department of Microbiology, University of Texas Health Science Center at San Antonio, San Antonio, TX

MOON CHEN, JR., Professor, Department of Epidemiology and Preventive Medicine, University of California, Davis, School of Medicine, Associate Director for Cancer Prevention and Control (Population Sciences), University of California, Davis, CA

HARVEY R. COLTEN, Vice President & Senior Associate Dean, Academic Affairs, Columbia University, Health Sciences and College of Physicians & Surgeons, New York, NY

ROBERT A. HIATT, Professor, Epidemiology and Biostatistics, UCSF Comprehensive Cancer Center, Population Sciences, San Francisco, CA

SHERMAN JAMES, Susan B. King Professor of Public Policy, Duke University, Durham, NC

ICHIRO KAWACHI, Professor of Social Epidemiology, Director, Harvard Center for Society and Health, Harvard School of Public Health, Boston, MA

CLAUDE LENFANT, President, World Hypertension League, Gaithersburg, MD

SPERO M. MANSON, Professor of Psychiatry, Head, American Indian and Alaska Native Programs, University of Colorado at Denver and Health Sciences Center, Denver, CO

JEANNE MIRANDA, Professor in Residence, University of California, Department of Psychiatry and Biobehavioral Science, Los Angeles, CA

KYU RHEE, Medical Director, Upper Cardozo Community Health Center, Washington, DC

LYNNE D. RICHARDSON, Associate Professor, Emergency Medicine, Director, Emergency Medicine Residency, Mount Sinai School of Medicine, Department of Emergency Medicine, New York, NY

ANTONIA M. VILLARRUEL, Professor, Director, Center for Health Promotion, University of Michigan, School of Nursing, Ann Arbor, MI

DAVID WILLIAMS, Harold Cruse Collegiate Professor of Sociology, Senior Research Scientist, Institute for Social Research, University of Michigan, Ann Arbor, MI

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IOM Staff

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AMY HAAS, Administrative Assistant
CARLOS GABRIEL, Financial Associate (until May 2005)
DAVID CODREA, Financial Associate

Reviewers

This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the National Research Council's (NRC's) Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process. We wish to thank the following individuals for their review of this report:

PAULA A. BRAVEMAN, University of California, San Francisco
H. JACK GEIGER, City University of New York Medical School
BRADFORD GRAY, The Milbank Quarterly, The Urban Institute
RUTH HANFT, James Madison University
ROBERT A. LOWE, Oregon Health & Science University
NICOLE LURIE, The RAND Corporation
JOHN E. MAUPIN, Meharry Medical College
RUBENS J. PAMIES, University of Nebraska Medical Center
TIMOTHY SIZE, Rural Wisconsin Health Cooperative

Although the reviewers listed above have provided many constructive comments and suggestions, they were not asked to endorse the conclusions or recommendations nor did they see the final draft of the report before its release. The review of this report was overseen by **NEAL VANSELOW,** Tulane University,

Professor Emeritus, and **DAVID KINDIG,** Wisconsin Public Health and Health Policy Institute, University of Wisconsin-Madison.

Appointed by the NRC and Institute of Medicine, they were responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the authoring committee and the institution.

Preface

Although the overall health of Americans has improved considerably over the past several decades, the health of racial and ethnic minorities and other populations continues to lag behind that of whites. For decades, there have been declarations identifying correction of health disparities as a national priority but progress has been slow, and the suffering, disability, and death continue. If the gaps between populations persist and some minority populations continue to grow disproportionately, within several decades most Americans will be members of populations at risk for disparate health.

Improving the situation requires much better understanding of health disparities. The National Institutes of Health (NIH) has supported and conducted extensive research related to minority health and health disparities. The NIH health disparities research effort was addressed by Congress with the "Minority Health and Health Disparities Research and Education Act of 2000." Among its provisions, the legislation called for establishing the National Center on Minority Health and Health Disparities (NCMHD) with two broad areas of responsibility: first, administration of extensive grants and awards aimed at strengthening the country's personnel and institutional capacities to conduct research on minority health and health disparities; and second, coordination of all health disparities research across NIH together with oversight of the development and implementation of an NIH-wide strategic plan for health disparities research. NCMHD was established in 2000 and, in 2004, asked the Institute of Medicine to assess the adequacy and coordination of the Strategic Plan that had been developed. The study committee began the review late in 2004 with completion targeted for late 2005.

The extensive Strategic Plan features three broad research, research capacity, and outreach goals along with detailed objectives. Included are the individual plans of 25 of the 27 Institutes and Centers, as well as 2 Offices within the Office

of the Director. As a catalogue of ongoing and intended health disparities research activity across NIH, it is impressive. As a strategy in a health disparities research campaign, it is a beginning.

To be sure, the effort faces strong challenges. The first is the nature of the research itself. The range of diseases and conditions for which there are differences spans virtually all biomedical disciplines. There are complex, interrelated social, economic, behavioral, health care, and other environmental aspects—and the differences, their features, and the roles of contributing factors vary among affected populations and subpopulations.

The review committee sees the opportunity and need for NIH to focus even more on health disparities as a research entity and move knowledge and understanding forward as no other agency or setting can. Along with understanding the biomedical aspects of diseases and conditions that are the manifestations of health disparities, there is need to know more about the contributions and interactions of core conditions and factors that may be common to the genesis of disparate health. The NIH should take leadership in helping to understand, further define, and develop methodology regarding health disparities research. As well, given the particular importance of the translation of new information into best practices in the care of patients, there is opportunity to better understand, design, and assess communication of health disparities information to health professionals and the public as a core NIH effort with much to be learned and applied.

A second challenge has to do with coordination and management of such an extensive plan and program across NIH where the Institutes and Centers have a degree of autonomy that can make it difficult to effect concerted programs. The challenge is an example of other efforts to achieve trans-NIH coordination of broad interdisciplinary programs, such as those organized for AIDS, obesity, and neuroscience. The extensive nature of the health disparities research effort requires that there be a well-structured effort with ongoing, continuous improvement of the plan and program that is the result of extensive involvement from within and from outside of NIH contributing to identification of research needs, assessments, evaluation and priority determinations. Along with central oversight and attention to the detailed aspects of the programs, there must be a broader view and vision and assurance that needed research areas are not neglected. Also, there is the opportunity to bring together and involve much expertise from across NIH and from across the nation to inform the NIH program, its planning, evaluation and priorities.

The Strategic Plan and its strategy for health disparities research can be strengthened as part of an integrated, cohesive, coordinated trans-NIH program, developed with the best available thought, addressing relevant, prioritized questions and issues with clearly initiated and evaluated programs, and with the production of information which allows the NIH, and the nation, to be assured

that needed research on health disparities is being addressed as effectively and expeditiously as possible.

Throughout the review, the Committee felt the implications and urgency of the task and brought to the review the utmost devotion and commitment. We are grateful for the expertise and efforts of the staff, including Faith Mitchell, the Project Director, Monique Williams, Program Officer, and Thelma Cox, Senior Program Assistant.

Dr. Elias Zerhouni, the Director of NIH, Dr. Raynard Kington, Deputy Director of NIH, and the NIH Office of Budget were forthcoming and most helpful. We are particularly grateful to the NCMHD and its Director, John Ruffin, and the staff for their intense devotion, cooperation and assistance and to the Institutes and Centers which provided valuable information and insights. We are thankful for the cooperation, responses, testimony and other information provided by the Institutes and Centers and Offices within the Office of the Director and those provided by the many distinguished individuals and devoted organizations.

Gerald E. Thomson, M.D., *Chair*
Committee on the Review and Assessment of the
NIH's Strategic Research Plan and Budget
to Reduce and Ultimately Eliminate Health Disparities

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